



SPOKANE OSTOMY SUPPORT GROUP NEWSLETTER

Affiliated with United Ostomy Association of America, Inc.

Published Quarterly by Local # 349 (SOSG) - Editor: Phillip R. Moyle (SOSG.Input@gmail.com)

Issue 16 - 3

Advocates for Ostomates & Caregivers

Summer 2016

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SUSIE & CAROL'S CORNER - WAZZUP

Spokane Ostomates Start Newsletter

by Susie Leonard Weller

Many thanks to Phil Moyle, our Spokane Ostomy Support Group Newsletter Editor, for his role in publishing our second edition! Ostomates, as well as ostomy nurses, have appreciated the compilation of upcoming meeting announcements and informative articles. This newsletter is now serving our entire region. Welcome to the new ostomy support group meeting at the Kootenai Medical Center in Coeur d'Alene, ID, who are also receiving this newsletter.

Carol initiated a new dimension of our monthly meetings to spotlight individual support group members and their contributions. This quarter we highlighted the following participants: Jim and Julie Price give a monthly reminder call to those not able to receive email announcements about the meeting; Dale and Shirley Neunschwander shared examples of being resilient with multiple health challenges and the power of loving spouses and friends to get through the hard times; Archie Oestreicher and Dan Ramsdell participated in a panel on tips for living well with a urostomy.

To continue getting better acquainted, please join us for our yearly social. The July 5th support group will meet for dinner at the downtown Perkins Restaurant at 6:30 p.m. at 12 E. Olive, near the Division Bridge and Convention Center (*Free parking*). Enjoy an Ostomy Bingo Game with prizes!

MEETINGS & ANNOUNCEMENTS

Spokane Ostomy Support Group (SOSG)

Meetings for ostomates & caregivers are held on the first Tuesday each month (February-November) 6:30-8 p.m.

**Providence Sacred Heart Medical Center
101 W 8th Ave, Spokane, WA 99204
Mother Joseph Room,
next to the cafeteria on L-3**

*** Please contact Susie Leonard Weller for questions and/or comments:**

call: 509-255-6676 or

email: *SOSG.Input@gmail.com*

All are welcome to join us!

Upcoming Meetings & Topics

- July 5 - Dinner Social, 6:30 p.m. meet @ Perkins Restaurant (downtown).**
- August 2 - How Many Ostomates Are There? Statistics & Other Fun Facts.**
- Sept. 6 - Ostomy nurses report on the International WOCN Conference.**
- Oct. 4 - Vendors – Ostomy Supply Reps.**
- Nov. 8 1 - Nutrition Tips for the Holidays.**

Regional / National Events

**6th National Conference, Irvine, CA
8 / 22-26 / 2017**

Speaking of games, try a Scavenger Hunt in this newsletter to answer the following questions: Who are some famous people who've had an ostomy? What are the national percentages of those with a colostomy, ileostomy or a urostomy? Can you name two products that can keep you hydrated and avoid a trip to the hospital for an IV? Which foods are the most likely to cause a blockage? When traveling, what should you carry in your wallet?

Stay tuned to explore new topics at our upcoming meetings that range from fun facts about ostomates to the latest information from the June, 2016 International Wound, Ostomy and Continence Nursing Society Conference in Montreal, Canada.

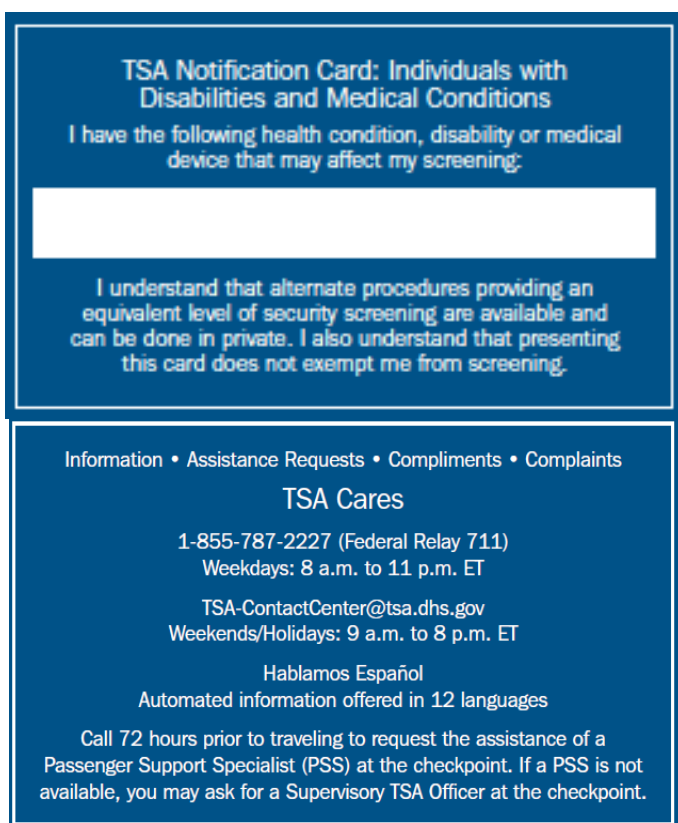
(Continued on page 2)



We welcome your ideas to strengthen our support meetings and this newsletter. Please send your suggestions to SOSG.Input@gmail.com by September 20th. Consider ways YOU can be of service, especially to newer ostomates! Thanks again to Rich Judd and Byram Healthcare for their assistance in publishing this newsletter. Contact Rich at rjudd@byramhealthcare.com to be added to the mailing list.

TRAVEL SEASON BONUS

Do You Know What This Is?



TSA Notification Card: Individuals with Disabilities and Medical Conditions

I have the following health condition, disability or medical device that may affect my screening:

I understand that alternate procedures providing an equivalent level of security screening are available and can be done in private. I also understand that presenting this card does not exempt me from screening.

Information • Assistance Requests • Compliments • Complaints

TSA Cares

1-855-787-2227 (Federal Relay 711)
Weekdays: 8 a.m. to 11 p.m. ET

TSA-ContactCenter@tsa.dhs.gov
Weekends/Holidays: 9 a.m. to 8 p.m. ET

Hablamos Español
Automated information offered in 12 languages

Call 72 hours prior to traveling to request the assistance of a Passenger Support Specialist (PSS) at the checkpoint. If a PSS is not available, you may ask for a Supervisory TSA Officer at the checkpoint.

The TSA has a **Disabilities & Medical Conditions Card** that travelers can print, fill out and bring with them to the security checkpoint. The cards have a space to enter information about any relevant health conditions or medical devices, though they also include the following caveat: "Presenting this card does not exempt you from screening." The card can be downloaded from the following site: https://www.tsa.gov/sites/default/files/disability_notification_card_508.pdf. We recommend that you check with the TSA and airlines to assure that the card will be honored.

NURSE'S CORNER - Q & A

By Rebecca Thomas, BSN, RN, CWOCN

1. When a patient with an ostomy is checked out at one of the local Outpatient Ostomy Clinics, what are the expectations for the patient, and what examination procedures are conducted?
 - For a pre-op visit, the expectations for the patient is to come with questions written down, bring a loved one or primary support person, and bring a list of current medications. We ask that the patients arrive 15 minutes prior to their scheduled appointment time to allow ample time to go through the check-in process so the actual appointment with the ostomy nurse can start on time. The goal of the pre-op visit is to acquaint the patient with the role of the Certified Ostomy nurse and living with an ostomy, answer questions, and select an appropriate site for the surgeon to place the stoma. Procedures for a pre-op visit may include asking the patient to stand, sit and lying down and assessing their abdomen. For post-op visits, the arrival schedule is the same. It's always a good idea to bring your current supplies and list of current medications with you. Some procedures during a post-op visit may include a digital exam, assessment of stoma and peri-stomal skin.
 - We also follow patients after ostomy surgery to provide ongoing education and support. It is a known fact that as things change in our life, our ostomy needs change so we can help people navigate those changes. Plus as new supplies are developed and released, we can help identify new options for you to consider.
2. What is the overall procedure?

An outpatient appointment generally takes 60 minutes. Arrive 15 minutes prior to your appointment time, go to surgery check-in on the Main Floor (past the elevators and before Thomas Hammer by the Care Shop). Once checked in, transport will be called and assist you over to the ostomy clinic. There the certified ostomy nurse will greet you and start the appointment/exam. Once the appointment is over, typically transport is called and will assist you back to the entrance/exit point near your vehicle.

(Continued on page 3)

NURSE'S CORNER - Q & A

(Continued)

3. How often is an exam recommended?

After surgery, we recommend patients return to the clinic for ongoing education and re-assessment at the following intervals: 1, 3, and 6 months post-op and then annually. Every patient with an ostomy should be seen by a certified ostomy nurse immediately post-discharge (within 2 weeks), whether in the clinic setting or by home health care.

4. Should the patient with an ostomy avoid eating before the exam? No, there is no need.

5. Is the appliance removed during the exam?

Typically the appliance may be removed to examine your peri-stomal skin and obtain accurate stoma measurements.

6. Should the patient bring a replacement appliance?

It is really important to always bring a spare, because it's possible we could be out of a certain product. However, there are many reasons why the ostomy nurse may decide to use your same appliance. For instance, we may be able to make minor adjustments to your existing pouching system to make it work.

7. Other factors and recommendations for an exam?

Often we find the person with an ostomy feels they are doing fine so don't need ongoing follow-up. However, in our experience we are able to identify things that can lead to problems that we can address before problems develop.

DIVERSION INSPIRATION & HUMOR

(submissions & ideas welcome)

By popular demand, we revisit *Ostomy Barbie*!



You know you have an ostomy when...
When you hear someone talking about a "one piece" or a "two piece" you think of ostomy bags, not swimsuits.

INTERESTING OSTOMY WEBSITES

(some may not be suitable for children!)

<http://uncoverostomy.org/2013/12/04/well-would-ya-look-at-that/>

<http://www.mirror.co.uk/news/real-life-stories/people-say-theyd-die-colostomy-7115390>

<http://www.healingwell.com/community/default.aspx?f=33&m=2550439>

<http://newbieostomy.com/get-support/ostomy-humor/>

http://www.livingwithastoma.co.uk/poems_ostomyLaughs.html



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***** "SEASONAL ARTICLE(S)" *****

How Many Ostomates Are There? Statistics & Other Fun Facts

by Phillip R. Moyle*

How many people have ostomies? And who? Maybe you can recognize some of these familiar names⁽¹⁾: Dwight Eisenhower, former US President; Bob Hope, entertainer/comedian/actor; Tip O'Neil, US Speaker of the House; Al Geiberger, professional golfer; Hubert Humphrey, US Senator; Loretta Young, actress; Rolf Benirschke, kicker for the San Diego Chargers⁽²⁾; Pope John Paul II⁽³⁾; and on and on. The Queen "Mum" had one too!

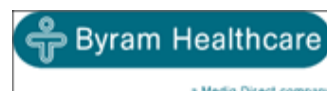
Members of Spokane Ostomy Support Group have wondered: "How many ostomates there are?" and "How many ostomy surgeries are performed annually in the US? North America? or world?" Responses ranged from a few thousand to hundreds of thousands of new ostomates each year! So what are the facts, , , the real numbers? Being a technical/numbers geek, I sought answers via the Internet. Perhaps the nature of the challenge is revealed in the title of an old but enlightening article, "Ostomies: No Longer the 'Secret Surgery'"⁽²⁾. To say the least, I was frustrated to find that data about ostomy surgeries and ostomates remain scanty, elusive, and exhibit a wide range of uncertainty. However, a high point of my research journey was discovering just how many members of our ostomate community there are, including many very accomplished celebrities who are out there living normal, active lives! And who would know?! My research revealed several informative articles which are listed in the *References Cited* section at the end of the article.

Research Findings – The Numbers (?): Let's take a look at some of those *fleeting numbers*.

- How many ostomy surgeries are performed in the US annually? Reports ranged from 100,000⁽²⁾ to 130,000⁽⁴⁾ ostomy surgeries each year in the US. The UOAA article⁽⁴⁾ also indicated a significant trend during the 2002-2007 study period: the proportion of temporary ileostomy surgeries increased relative to permanent ostomy surgeries:

“., the number of people with a new, permanent ileostomy has increased by a little over four percent per year, but the largest percentage increase has been in the number of new, temporary ileostomies at nearly nine percent per year. By 2007, new, temporary ileostomies dramatically outnumbered new, permanent ileostomies. The number of new urostomies was pretty static from 2002-2006 but showed an increase of 12 percent in 2007.”

Possible causes for this trend were not addressed in the article, so we can only speculate: Changing health condition of patients? New treatment strategies? Increased intestinal diseases? Etc. What do you think?
- How many ostomates are in the US? Numbers reported were all over the place. The lowest population of ostomates reported was 450,000⁽⁵⁾, and the highest number, ironically reported by the UOA in 1982, was a range of 1.5 to 2 million in the US⁽²⁾. Other "estimates" found in various sources were: 500,000⁽³⁾; and 800,000^(3*) with a 3 percent reported growth rate. The 2009 UOAA article⁽⁴⁾ reported about 730,000 ostomates in 2002 increasing at a rate of about 1.5 percent per year.



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Projecting the UOAA-reported data indicates a current (2016) total US ostomate population of approximately 900,000.

WOW, what a wide range of numbers! *(Continued on page 5)* Additional interesting statistics reported^(3, 4) include the following tidbits:

- Age – percent of new ostomy surgery by age range:
 - 2-3% with a new ostomy are below 18
 - 9% are between 18-44
 - 38% are between 45-64
 - 45% are between 65-84
 - 6% are 85 and over
- Age - average ages by type of ostomy:
 - Colostomy = 70.6 years old;
 - Ileostomy = 67.8 years old; and
 - Urostomy = 66.6 years old.
 - Overall average age of an ostomate in the US is about 68.3 years old (therefore, a Medicare beneficiary).
- Type of Ostomy - studies of the frequency of the three most common types of ostomy surgeries indicate:
 - Colostomy = 36.1%;
 - Ileostomy = 32.2%; and
 - Urostomy = 31.7%.
- Gender - a consumer survey in 1998 of more than 1,400 people with an ostomy found that 57% were female. However, the UOAA article⁽⁴⁾ offered considerable more detail:
“There is very little difference in the proportion of males and females for those with temporary colostomies and permanent ileostomies. Men outnumber women by around 55:45 for permanent colostomies and temporary ileostomies, but the largest difference between the sexes is for urostomies among whom males outnumber females by 73:27. Adding together all types of ostomy, in 2007, men undergoing surgery outnumbered women by 58:42 with a slight trend towards this gap widening.”

So why don't we and the medical community have a more accurate idea of the number and types of ostomates in the US? Following is a bullet list of possible contributing factors:

- Administrative: Hospital and health insurance reporting codes used in the US to track medical conditions and procedures lack specificity and consistency, especially for ostomy-related conditions. Coding is commonly disease-specific, rather than being listed by procedure. As a result, this makes ostomy surgeries more difficult to track.
- Geographic: Medical conditions and treatment, the quality of medical facilities and expertise, and the availability of health insurance can vary considerably in different parts of the country. This too may contribute to difficulties with tracking ostomy procedures.
- Technology: Frequent improvements in technology and expertise resulting from medical research contribute to higher success rates for ostomy surgery and long-term care. However, repeated medical procedure improvements may also contribute to tracking challenges due to medical coding adjustments.



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- **Funding:** Given the complexity of collecting accurate data on ostomy surgeries and ostomate populations, substantial funding would be required to conduct the studies necessary to continuously track all relevant factors.

Recommended Solution Pathway (Continued on page 6) The UOAA and related organizations could promote and work with the National Institutes for Health and Medicare (US Department of Health and Human Services) to fund and conduct such research. Ostomy supply companies may be the best source of reliable data on ostomate populations and types. Let's continue to partner with our local healthcare providers and vendors to collect and track local and regional data.

Clearly no one really knows how many ostomates are in the US, but there are many of us. It is inspiring to know that we are in good company, and that we live normal, productive lives. Finally, I am thankful for the benefits and contributions that the Spokane Ostomy Support Group provides to our community.

References Cited:

- 1 - Famous Ostomates. Dec. 19, 2015. <http://www.colomajic.com/blog-posts/famous-ostomates/>.
- 2 - Ostomies: No Longer the 'Secret Surgery'. Judy Klemesrud, May 3, 1982. The New York Times, <http://www.nytimes.com/1982/05/03/style/ostomies-no-longer-the-secret-surgery.html?pagewanted=all>.
- 3 - The Ostomy Files: Ostomy Statistics: The \$64,000 Question. Gwen B. Turnbull. June 1, 2003. Ostomy Wound Management, Volume 49 - Issue 6.
- 3* - Frost predicts steady growth for ostomy market. *Home Care Monday*. June 3, 2002. (cited in Turnbull, 2003, but could not retrieve from <http://www.homecaremag.com/homecaremonday>)
- 4 - Ostomy Census – Surgeries Performed Each Year and the Current Population.” Colin Cooke. Dec. 2009. The Phoenix (UOAA).
- 5 - Ostomy surgery in the United States. The Oryx Group. February 1997. Proprietary data on file. ConvaTec, a Bristol-Myers Squibb Company.

Acknowledgements: Thanks to Ian Settlemire, Publisher, Phoenix Magazine (UOAA) for providing a digital copy of Colin Cooke's definitive article⁽⁴⁾. Also, I appreciate the many helpful review comments and suggestions offered by our own Susie Leonard Weller.

* Note that in the next months I intend to research and hope to write an article about the history of ostomies as well as current trends. In the future, I would also like to address the effects that the American lifestyle(s) - diet, stress, environmental (what chemicals are in your garage), etc. - have on these trends.

What CAN I Eat?

by Susie Leonard Weller

Do you know which foods can cause a blockage, gas, odor, constipation or diarrhea or cause gas? Although each person reacts differently to specific foods, consider these suggestions from





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the United Ostomy Association of America. The chart below summarizes the main foods that can help or hinder how well you live with your ostomy.

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| Stoma Obstructive | Relieve Constipation | Relieve Diarrhea or Thicken Output |
|----------------------|------------------------------------|------------------------------------|
| Apple peels | Coffee & other hot beverages | Applesauce |
| Raw cabbage | Cooked fruits | Bananas |
| Corn | Cooked vegetables | Boiled rice |
| Coconut | Fresh fruits | Peanut butter |
| Oranges | Fruit juices, i.e. prune juice | Pectin |
| Nuts & Seeds | Prunes and raisins | Tapioca |
| Pineapple | Licorice | |
| Popcorn | Fiber if tolerated, ie. Metamucil™ | |
| | Water | |
| Gas Producing | Odor Producing | Odor Control |
| Alcoholic beverages | Asparagus | Buttermilk |
| Carbonated beverages | Baked beans | Cranberry juice |
| Beans | Broccoli | Orange juice |
| Soy | Cabbage | Parsley |
| Cauliflower | Eggs | Tomato juice |
| Cucumbers | Fish | Yogurt |
| Dairy products | Garlic | |
| Onions | Onions | |
| Chewing Gum | Strong cheeses | |

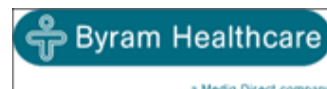
Those with a urostomy have few dietary restrictions. However, they are at a higher risk for urinary tract infections and becoming dehydrated. Here are some tips to avoid this:

- Drink about 10-12 glasses of water or juice—more if your urine has a dark color or a strong odor.
- Be aware that drinking more than a few cups of caffeinated drinks can cause dehydration.
- Drink pure, unsweetened cranberry juice or take cranberry tablets to avoid UTI's (Urinary Tract Infections).
- Reduce urinary crystals on the stoma or skin by keeping your urine slightly acidic by drinking cranberry juice. These crystals can appear as white, gritty particles which irritate the stoma. Use a cloth with equal parts of water and white vinegar to clean the stoma. However, if you're taking blood-thinning medications, such as Warfarin™, avoid drinking cranberry or grapefruit juice.

Maintain Your Fluids & Electrolyte Balance to Avoid Dehydration

Monitor your electrolyte balance of sodium, potassium and magnesium, to prevent a trip to the hospital for IV hydration. When you've had a section of your colon removed, there is a greater possibility for an electrolyte imbalance. Diarrhea, excessive perspiration, vomiting and short bowel syndrome can increase this risk.

Avoid becoming dehydrated, especially during the upcoming warmer months. Symptoms of dehydration include: thirst; dry or sticky mouth; decreased urination; darker colored urine; dry, cool skin; headache; or muscle cramps. If you notice any of these signs of dehydration, try





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drinking sports drinks with electrolytes or a medical grade electrolyte solution. Lyte Balance™ is a concentrated liquid electrolyte made in Liberty Lake that can be added to juice. H2ORS™ is a powdered electrolyte drink mix. These specialty blends are recommended by the World Health Organization to reverse dehydration and the need for IV therapy.

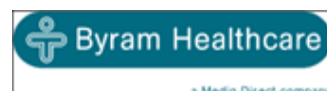
Your diet should regularly include fluids and foods rich in electrolytes. A general rule is to “salt” foods to taste.” Do not exclude sodium in the diet. Most fruits and vegetables—especially bananas and avocados-- are good sources of potassium and magnesium.

General Nutritional Tips for Ostomates

- Slow down and chew your food really well.
- Avoid skipping meals—empty bowels can produce gas.
- Eat small, frequent meals.
- Eat your largest meal in the middle of the day.
- Drink 6-8 glasses of fluids daily—but not with meals.
- Decrease gas by avoiding drinking carbonated beverages, especially soda pop and beer.
- Maintain your electrolyte balance with sufficient sodium, potassium and magnesium.
- Limit foods containing simple sugars –candy, pastries, and sweetened drinks. They can aggravate diarrhea.
- Avoid heavily spiced foods which can cause diarrhea.
- Consider eating a “low residue” diet that eliminates bulk-forming, hard-to-digest or high-fiber foods.
- Track your reactions to specific dairy products. Some people are lactose (milk) intolerant.
- Maintain a healthy weight. An increase or loss in weight can impact the fit and wear time of your wafer.

Your food choices make a big difference. Enjoy feeling better and avoid problems with your ostomy by eating healthier!

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IMPORTANT SOSG SUPPORT CONTACTS

Providence Sacred Heart Outpatient Ostomy Clinic - M-F 8-2:30 (509-474-4950), leave a message if you don't reach someone live); appointments & MD referral required; No walk ins; Can be seen for follow up, checkup, questions, problems.

Deaconess Medical Center - Wound Center - M-F 9:00-3:00 (509- 473-7290); appointments & MD referral required.

Ostomy Visitor Program - Those who have had or are facing potential ostomy surgery should contact Carol Nelson (509-433-1242; carol@nelsonwheat.com) to arrange contact with or a visit from an experienced and trained ostomate Visitor.

Inland Northwest Bladder Cancer Support Group - A support group for urostomates and bladder cancer patients. Members meet the first Tuesday of the month at 5 p.m., Perkins Restaurant, on 12 E. Olive, in downtown Spokane. Contact Alan Roecks (509) 269-8026, or email him at BladderCancerGroup@gmail.com.

United Ostomy Association of America (UOAA) - (800-826-0826); P.O. Box 525, Kennebunk, ME 04043-0525; Link: <http://www.ostomy.org/Home.html>.

Phoenix Magazine - (800-750-9311); The Phoenix Magazine, P.O. Box 3605, Mission Viejo, CA 92690; Link: <http://www.phoenixuoaa.org/> (get a free sample copy).

Primary Producers of Ostomy Products:

Hollister 1-888-808-74556

Coloplast 1-888-726-7872

Convatec 1-800-422-8811

<http://www.hollister.com/>

<http://www.coloplast.us/Ostomy>

<http://www.convatec.com/ostomy/>